

Federation of Families for Children's Mental Health of South Carolina





Family–Driven and Youth–Guided Care: Making the Connection between Shared Responsibility and Better Outcomes

- ▶ PCSC Conference
- ▶ September 16, 2016



Presented
by

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and

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I am a parent.



How do you define family?



How we define “Family Member



A FAMILY is the group of individuals who support the child emotionally, physically, and financially.

- ▶ A family includes individuals of various ages who may be biologically related, related by marriage, or not related at all;
- ▶ Each family has a culture of its own that influences how the family approaches daily tasks and challenges; and
- ▶ Families work in different ways and have different resources at their disposal.



A family member is an individual who is a primary caregiver for a child, youth, or adolescent with a serious emotional disturbance (an emotional, behavioral, or brain disease or substance use disorder).

- 🧑 The primary caregiver may be provided with a significant level of support by extended family members.
- 🧑 Families who have children, youth, and adolescents with a serious emotional disturbance are organized in a wide variety of configurations, regardless of social or economic status.
- 🧑 Families can include biological parents and their partners, adoptive parents and their partners, foster parents and their partners, grandparents and their partners, siblings and their partners, kinship caregivers, friends, and others as defined by the family.

Evolution of Family Involvement



- ▶ The mental health care system was not working for families.
- Families suffered from “shame and blame”.
- Families were labeled dysfunctional.
- The service system was fragmented.





1982 *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services* by Jane Knitzer

1989 Families as Allies training developed by Portland State University
"Next Steps" Conference by Portland State University

Establishment of Federation of Families for Children's Mental Health
(National Federation of Families for Children's Mental Health)

1993 Inclusion of Family Voice was required in the Children's Mental Health Initiative (Systems of Care) Guidance for Applications (GFA)

1999 Family Involvement was required in all grant applications

2000 Family Professional Partnerships were formed



- ▶ 2003 President's New Freedom Commission on Mental Health issued *Achieving the Promise: Transforming Mental Health Care in America*
 - *Goal 2: Mental Health Care must be "consumer and family-driven"*
- ▶ 2005 Family-Driven was written into the Guidance for Applications as the preferred language for family involvement and the National Federation of Families developed the training curriculum



Goal 1

Americans Understand that Mental Health Is Essential to Overall Health

Goal 2

Mental Health Care Is Consumer and Family Driven

Goal 3

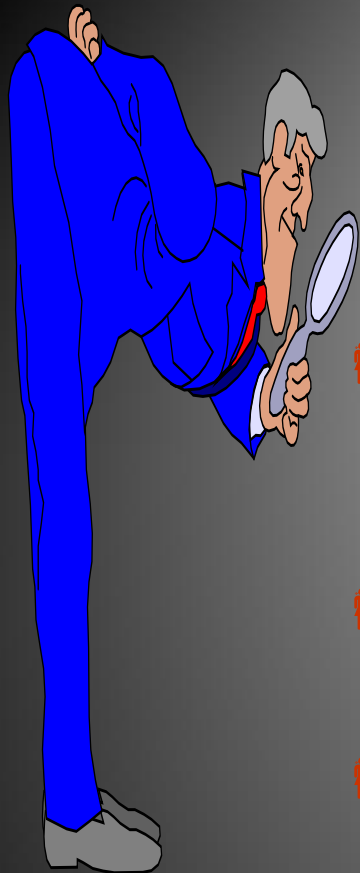
Disparities in Mental Health Services Are Eliminated

Goal 4

Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice

Goal 5 Excellent Mental Health Care Is Delivered and Research Is Accelerated

Goal 6 Technology Is Used to Access Mental Health Care and Information



Finding the Definition for Family-Driven Care

- Expert professional and family panel - culturally diverse, different perspectives, and geographically distributed;
- Interviews with recognized leaders in the family movement;
- Open forum discussions held at training institutes and conferences;
- Literature review conducted;
- Feedback solicited from system of care communities and family-run organizations; and
- Reactions gathered at presentations like this one.

Definition of Family Driven Care



Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:

- ▶ choosing supports, services, and providers;
- ▶ setting goals;
- ▶ designing and implementing programs;
- ▶ monitoring outcomes;
- ▶ participating in funding decisions;
- ▶ and
- ▶ determining the effectiveness of all efforts to promote the mental health and well being of children and youth.

Highlights of Family–Driven Care



- ▶ Families get all the information needed to make better choices and funding mechanisms support their choices.
- ▶ Families, administrators, and providers share power, authority, and control over decision–making and share responsibility for outcomes.
- ▶ Family and youth input steer decision making about all aspects of service and system design, operation, and evaluation.
- ▶ Family–run organizations have resources to sustain an independent family voice for system transformation.

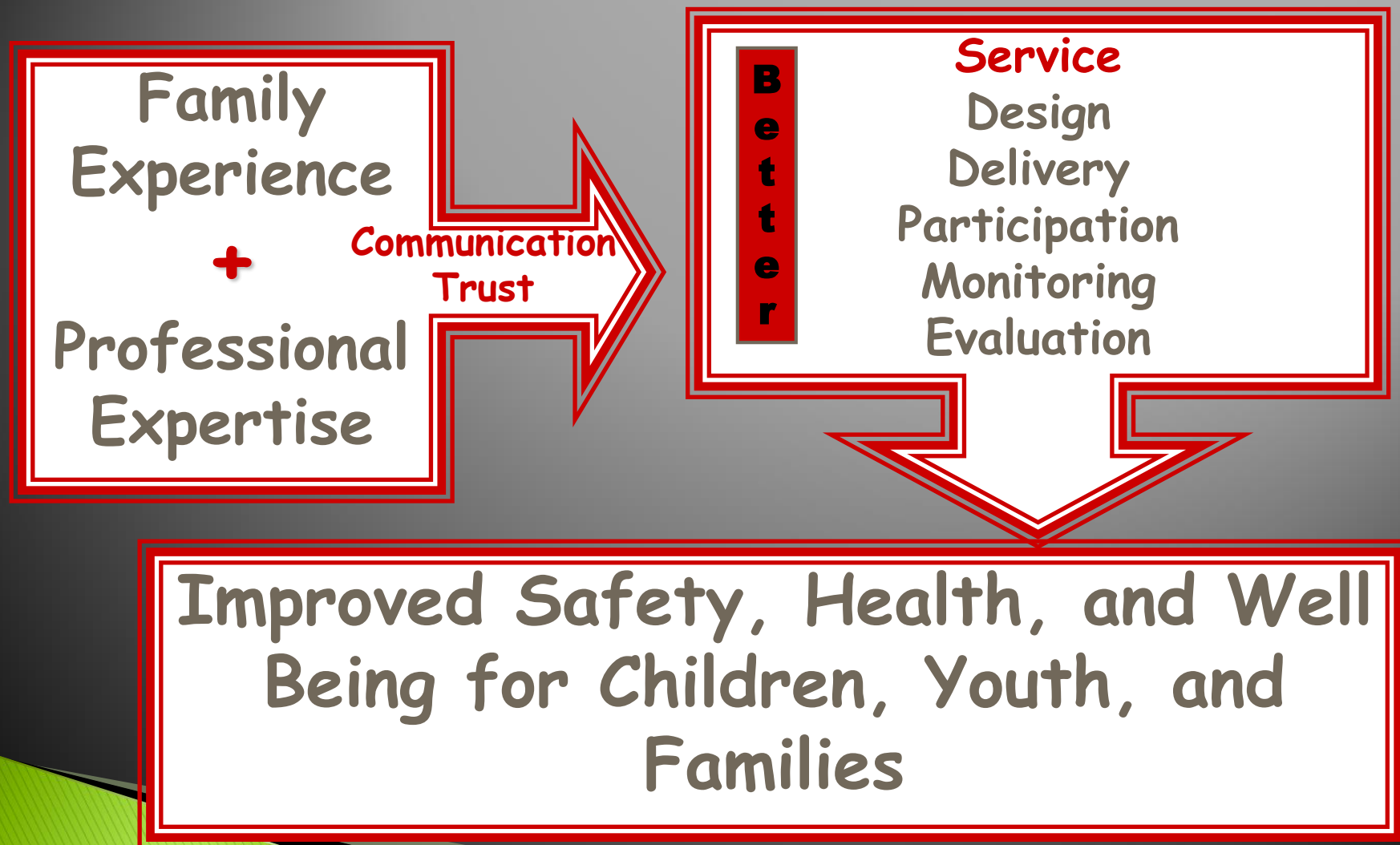
More Highlights of Family-Drive Care



- ▶ Agencies and providers *give staff the necessary support and resources* to change practice.
- ▶ Everyone is *respected and trusted* and it is safe to speak honestly.
- ▶ *Stigma* is reduced and communities value and embrace *diversity*.
- ▶ Every child has a *family voice to advocate* on their behalf.

Practice Base for Family-driven Care

Collaborative Partnership





What Family-Driven Care is NOT!

It is not a tool for families to dictate what everyone should and should not do

It does not mean that providers place the entire decision making on families

What does family-driven care look like?



- Families don't feel judged or blamed because of their child's behavior
- Families can ask for the services and supports they need and maintain a sense of dignity and respect
- Families feel valued and validated
- Families express challenges, ideas, or plans without fear of alienation or retribution



- ▶ Families are not expected to have all of the answers
- ▶ Policies are in place that support family-driven care
- ▶ Families are actively involved in evaluating the service system and the decision making process
- ▶ Resources and support are given to families in preparation for all meetings

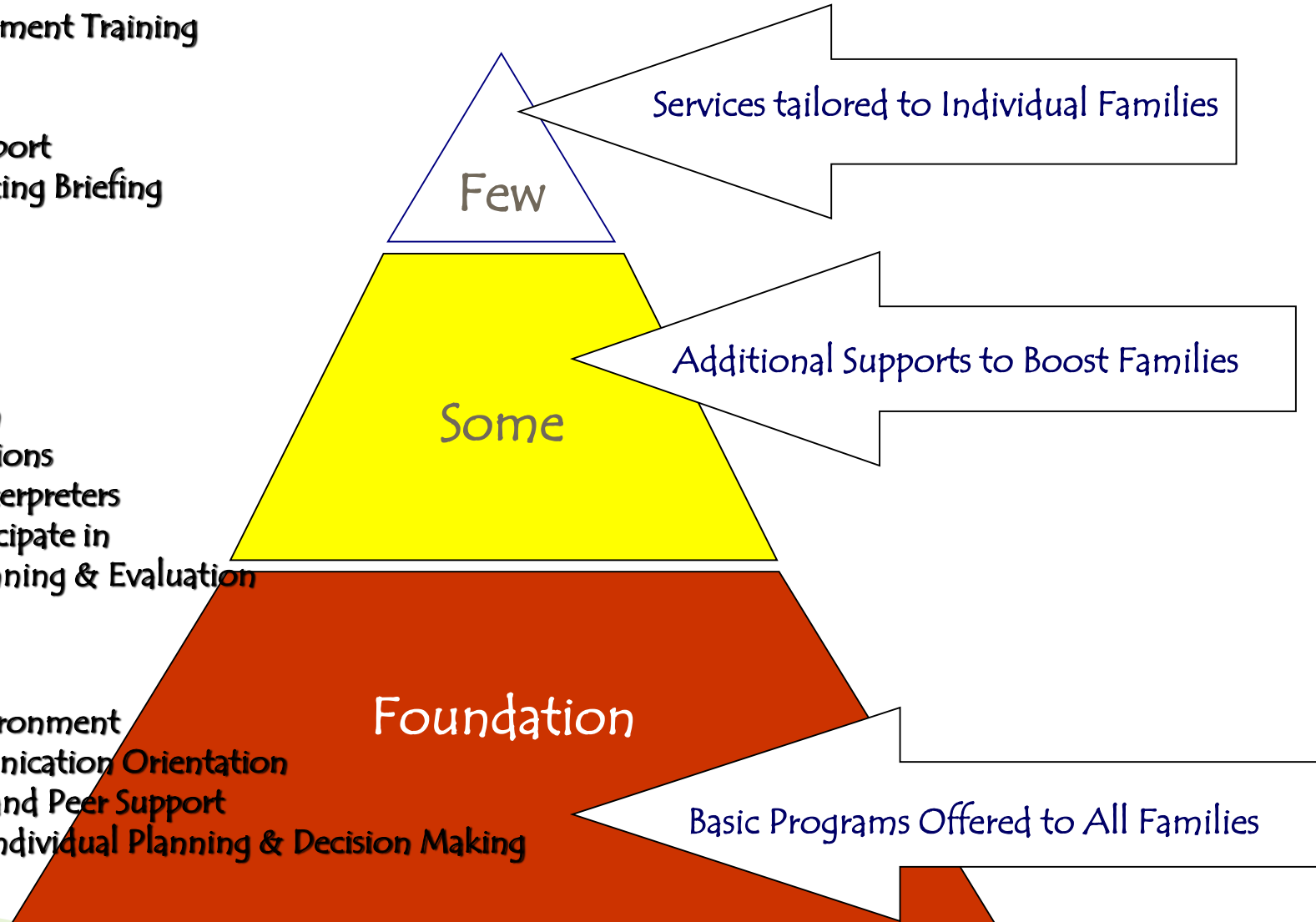
EXAMPLES

3 Levels of Family-driven Care

- ✓ Behavior Management Training
- ✓ Peer Mentor
- ✓ Home Aide
- ✓ Personalized Support
- ✓ Individual Reporting Briefing

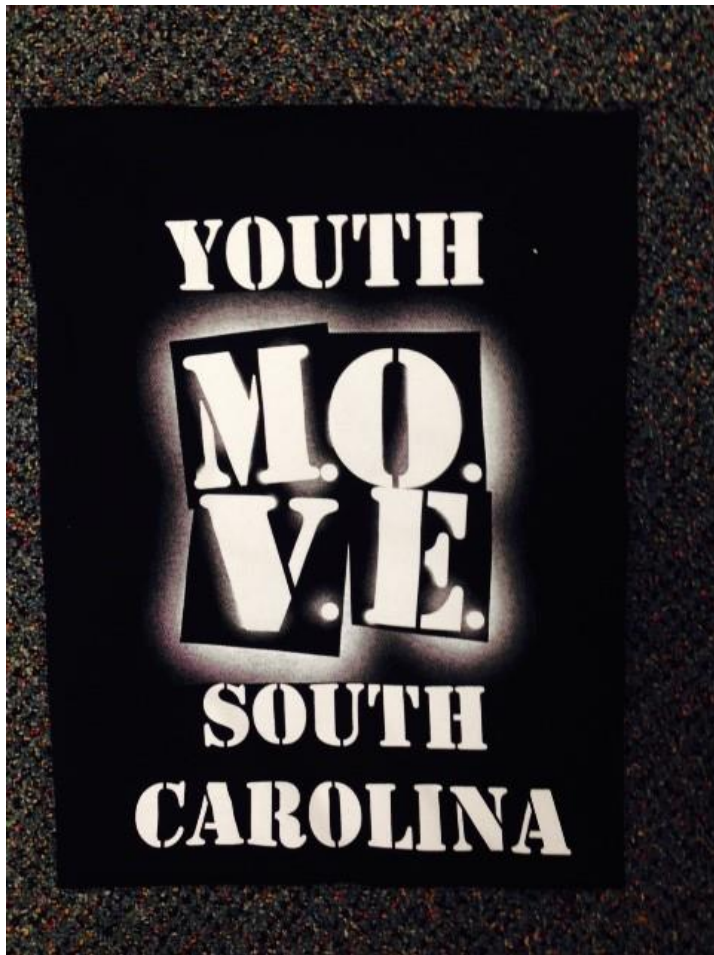
- ✓ Child Care
- ✓ Transportation
- ✓ Parent Education
- ✓ Cultural Adaptations
- ✓ Translation & Interpreters
- ✓ Supports to Participate in
- ✓ Institutional Planning & Evaluation

- ✓ Welcoming Environment
- ✓ Routine Communication Orientation
- ✓ Social Activities and Peer Support
- ✓ Participating in Individual Planning & Decision Making

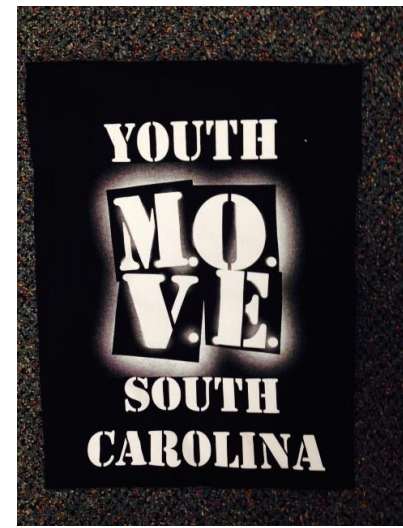




- ▶ **Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation.**

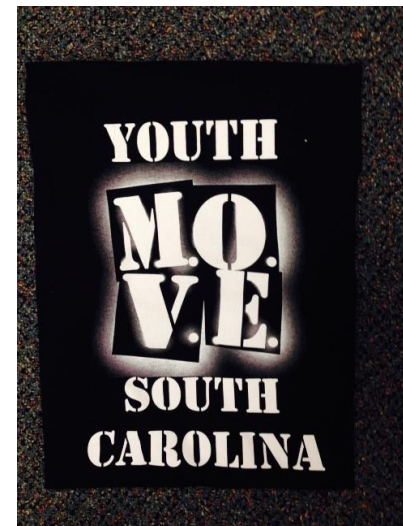


Youth Guided Care



Authentic Youth Voice

- ▶ Collective
- ▶ Connected
- ▶ Empowering
- ▶ Equitable
- ▶ Focused
- ▶ Healthy
- ▶ Learning
- ▶ Mutually Beneficial
- ▶ Relevant
- ▶ Responsible
- ▶ Substantive
- ▶ Self-Motivated



Key 1: don't fool the youth



Key 2: Work *with* youth – not *for* youth.



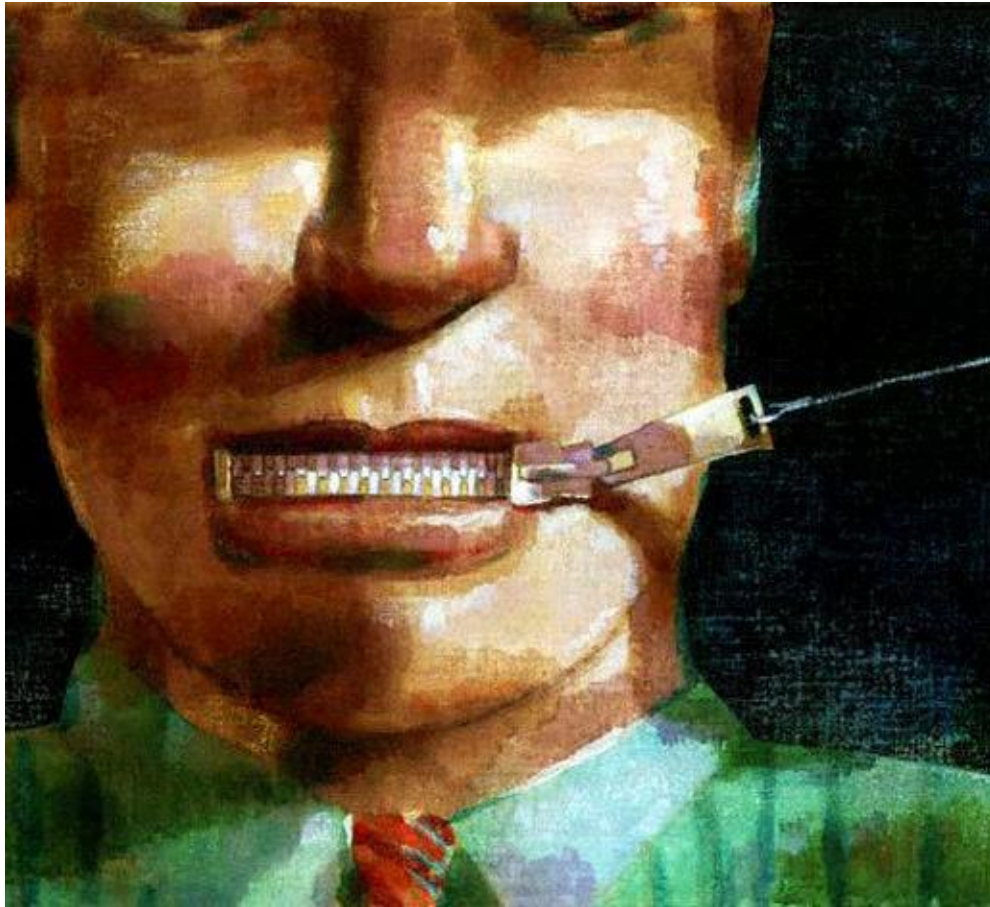
Key 3: Make having fun powerful.



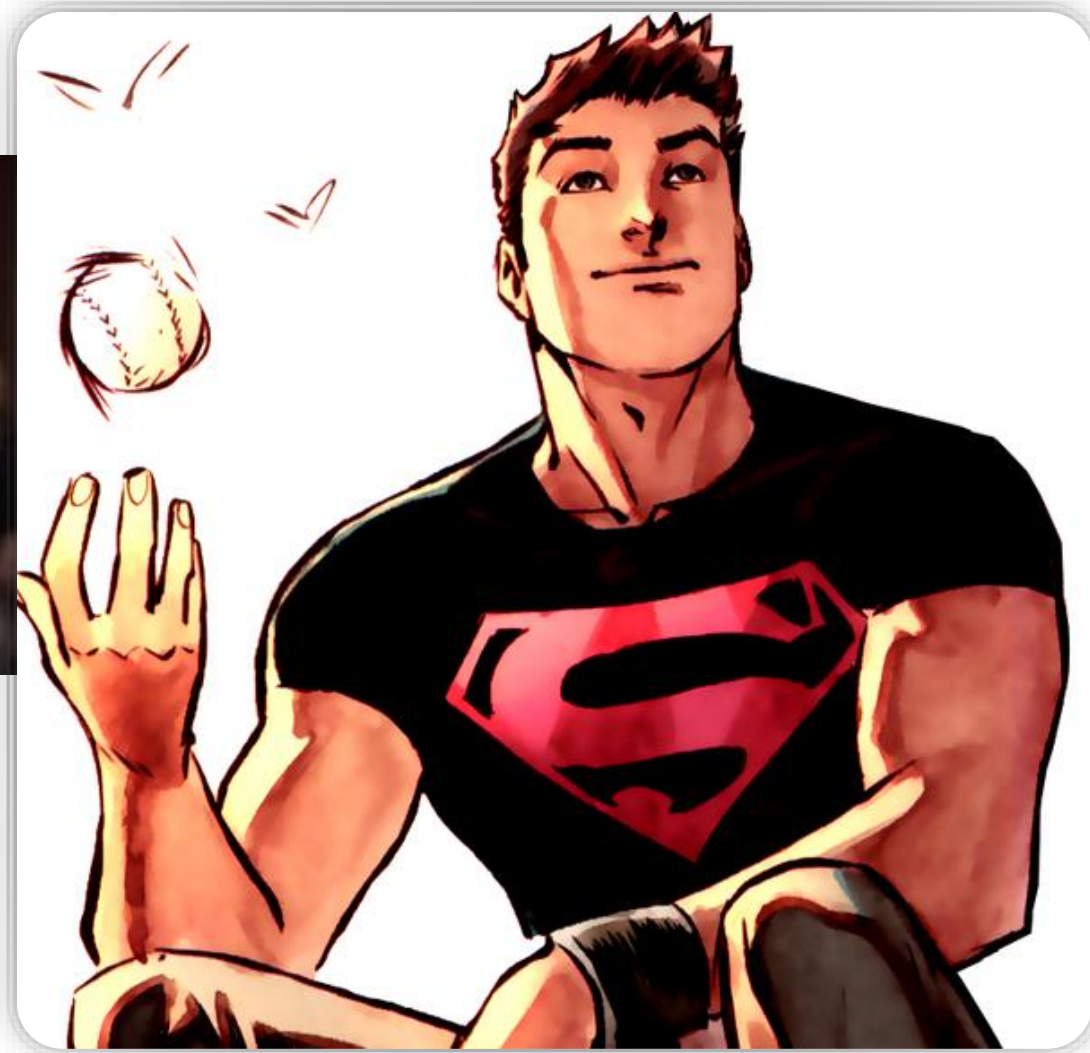
Key 4: Embrace change.



Key 5: Don't talk about “youth problems” anymore.



Key 6: Teach youth about adultism when they are young..



Key 7: Acknowledge young people in significant ways.



NATIONAL
YOUTH
AWARDS



THE
YOUTHEES

Key 8: Engage young people in something greater than themselves.



10 Guiding Principles

- ▶ Families and youth are given accurate, understandable, and complete **information necessary to set goals and to make choices** for improved planning for individual children and their families.
- ▶ Families and youth, providers and administrators **embrace the concept of sharing decision-making** and responsibility for outcomes.
- ▶ **Families and youth are organized** to collectively use their knowledge and skills as a force for systems transformation.
- ▶ Families and family-run organizations engage in **peer support activities** to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
- ▶ Families and family-run organizations provide **direction for decisions that impact funding** for services, treatments, and supports.
- ▶ Providers take the **initiative to change practice** from provider-driven to family-driven.
- ▶ Administrators **allocate staff, training, support and resources** to make family-driven practice work at the point where services and supports are delivered to children, youth, and families.
- ▶ Community **attitude change** efforts focus on removing barriers and discrimination created by stigma.
- ▶ Communities **embrace, value, and celebrate the diverse cultures** of their children, youth, and families.
- ▶ Everyone who connects with children, youth, and families continually advances their own **cultural and linguistic responsiveness** as the population served changes.

PARADIGM SHIFT: The Changing Role for Families and Youth



	Provider Driven	Family Driven
Source Of Solutions	Professionals and agencies	Child, family, and their support team
Relationship	Child and family viewed as a dependent client expected to carry out instructions	Partner/collaborator in decision making, service provision, and accountability
Orientation	Isolating and "fixing" a problem viewed as residing in the child or family	Environmental approach enabling the child and family to do better in the community
Assessment	Deficit oriented	Strengths based

PARADIGM SHIFT: The Changing Role for Families and Youth



	Provider Driven	Family Driven
Planning	Agency resource based	Individualized for each child and family
Access To Services	Limited by agencies menus, funding streams, and staffing schedules	Comprehensive and provided when and where the child and family require
Expectations	Low to modest	High
Outcomes	Based on agency function and symptom relief	Based on quality of life and desires of child and family

Values Base for Family-driven Care

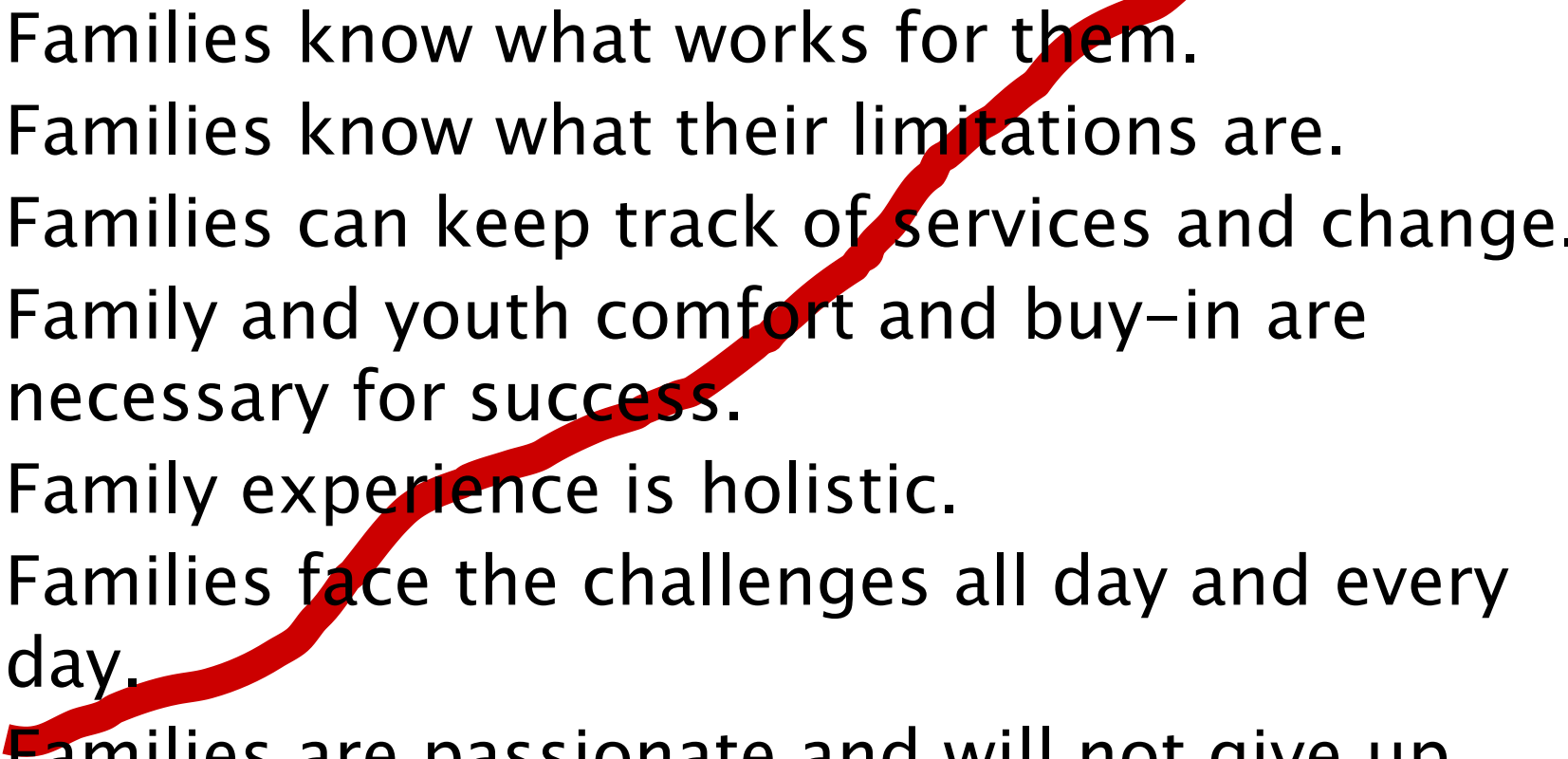


- ▶ It is the RIGHT thing to do.
- ▶ It fulfills the promise of “nothing about us without us.”
- ▶ It supports a professional code of ethics.
- ▶ It enables professionals and providers to “start where their client is at.”

Systems are beginning to mandate family-driven and youth-guided care.

Knowledge Base for Family-driven Care

TO GET BETTER RESULTS
TO CHANGE SYSTEMS

- 
- ▶ Families know what works for them.
 - ▶ Families know what their limitations are.
 - ▶ Families can keep track of services and change.
 - ▶ Family and youth comfort and buy-in are necessary for success.
 - ▶ Family experience is holistic.
 - ▶ Families face the challenges all day and every day.
 - ▶ Families are passionate and will not give up.
 - ▶ Families have credibility.



- ▶ **Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation.**

SAGE ON THE STAGE *OR* GUIDE ON THE SIDE?







Guide on the Side or Sage on the Stage

- ▶ 1. Whose idea is it?
- ▶ 2. How vocal were families during discussions?
- ▶ 3. Is what the family said REALLY represented in
- ▶ 4. Did I give families everything they need in order to be actively engaged?
- ▶ 5. Was there balance (equity) in the meeting/forum, etc.?
- ▶ 6. Did I champion the voices of families and youth in the meeting?
- ▶ 7. Did I offer support to the ideas expressed by families at....

The Benefits



- ▶ 1. Families become empowered by enhancing their vision of themselves and other families like them.
- ▶ 2. Providers benefit by having fully engaged partners in planning both on the practice and on the organizational levels.
- ▶ 3. Systems benefit from having a strong, sustainable family voice to guide them as policy is crafted.







Contact Us to Schedule a Training

- ▶ Federation of Families of SC
803.772.5210 toll free 866.779.0402.
- ▶ www.fedfamsc.org
- ▶ www.facebook.com/FederationSC
- ▶ www.facebook.com/YouthMoveSC

Thanks for coming!



“Not everything that is faced can be changed, but nothing can be changed until it is faced.”

Resources



National Federation of Families

- The Evolution: Family–Driven Care as a Practice

www.ffcmh.org

Family–Driven Care: Are we there yet?

A Road map for system transformation for family members, educators, and mental health professionals (Osher, Osher & Blau, 2006)

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